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Perceived control in health care: A conceptual model based on experiences of frail older adults



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ABSTRACT

Frail older adults are increasingly encouraged to be in control of their health care, in Western societies. However, little is known about how they themselves perceive control in health care. Therefore, this study aims to investigate the concept of health care-related perceived control from the viewpoint of frail older adults. A qualitative interview study was conducted following a Grounded Theory approach. Thirty-two Dutch frail older adults, aged 65 and over, participated in 20 in-depth interviews ($n = 20$) and three focus group discussions ($n = 12$). Data were analysed according to techniques of coding and constant comparison. From this analysis constituting factors of perceived control emerged, providing elements of a conceptual model. Perceived control reflects the feeling or belief that health care is *under control*, which is constituted by five, either internal or external, factors: (I) self-confidence in organising professional and/or informal care, (II) self-confidence in health management in the home setting, (III) perceived support from people in the social network, (IV) perceived support from health care professionals and organisations, and (V) perceived support from (health care) infrastructure and services. Therefore, the concept does not only consist of people's own perceived efforts, but also includes the influence of external sources. Our conceptual model points out what external factors should be taken into consideration by health care professionals and policy makers when enhancing older people's perceived control. Moreover, it can serve as the basis for the development of a measurement instrument, to enable future quantitative research on health care-related perceived control among older adults.

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Introduction

Background

Due to the increase of life expectancy, and the baby boom generation entering their third life phase, Western societies undergo a rapid growth of the proportion of older adults (Knickman & Snell, 2002; Zweifel, Felder, & Meiers, 1999). Consequently, there will be growing numbers of older people who cope with multiple and/or chronic health conditions (De Bruin et al., 2012; World Health Organization, 2009) who likely require more extensive forms of health care (Eklund & Wilhelmson, 2009). To face up to this development governments of ageing populations need to adapt their health and care policies. A trend that can be observed is the rising focus of these governments on the encouragement of older adults to be in *control* of their health and health care (Angus & Reeve, 2006; Clark, 1987; Martin-Crawford, 1999; Roberts, 1999). In the Netherlands for instance, the current policy discourse stresses that older adults should function as independently as they possibly can (Da Roit, 2012).

Given this development, it is urgent to foster scientific research on the concept of *control* in health care among older adults, in particular among those who are frail. Often, these people use multiple types of care, where issues of collaboration and integration of care between different care providers, interactions between informal and professional caregivers, and the loss of privacy may create situations where maintaining control is both important to streamline care and also is harder to realise. However, up to now, there is only limited understanding of the conceptualisation of health care-related control. Especially, the perceptions of the target group are not investigated sufficiently.

This article addresses the concept of perceived control in relation to health care, from the viewpoint of frail older adults, covering various types of care and a variety of settings; in the private sphere as well as in the office of the professional. We focus on the constituting factors that form perceived control in health care among frail older adults, a conceptual model that summarises these factors, and the reflection on how these affect perceived control, as well as the role of perceived 'personal' control in this respect.

For our work, we chose to start from the concept of *perceived control*, because it is a neutral psychological term with a broad theoretical basis, encompassing both components of self-efficacy and locus of control (Skinner, 1996; Wallston, Wallston, Smith, & Dobbins, 1987). It refers to the belief that one can determine one's internal states and behaviour, influence one's environment, and/or bring about desired outcomes (Wallston et al., 1987, p. 5). We consider that its general theoretical basis is a good frame for the domain-specific concept of health care-related perceived control that we intend to explore, as we expect that control within the context of the health care process covers a wide repertoire of thoughts, actions, and evaluations of a diversity of situations in this process, to which elements of both self-efficacy and locus of control are applicable.

Literature overview

Much has been written about the concept of *control* (Skinner, 1996; Walker, 2001; Wallston et al., 1987), as well

as about concepts like *mastery* (Pearlin & Schooler, 1978; Skaff, Pearlin, & Mullan, 1996; Younger, 1991), *self-efficacy* (Bandura, 1977), *locus of control* (Levenson, 1981), *empowerment* (Hage & Lorensen, 2005; Martin-Crawford, 1999; Zimmerman, 1995; Zimmerman & Rappaport, 1988), and *sense of agency* (Hitlin & Long, 2009). All of these are conceptually associated, but being used in different theoretical traditions, e.g. psychology (*mastery, control*), or anthropological work (*empowerment, agency*). However, many of these concepts have definitions with a strong theoretic and/or generalist fundament, and are mostly discussed in the context of rather broad domains, such as life, the life-course, or well-being.

The studies that specifically include the older population in this regard mostly investigated the course, the influential factors, and associated characteristics of control or control-related concepts. For example, Schieman and Turner (1998) found that higher age and disability were related to lower levels of *mastery*; and higher education levels were believed to predict greater *personal control* (Hitlin & Long, 2009). Moreover, Pearlin, Nguyen, Schieman, and Milkie (2007) noticed that extended education would indirectly influence the *life-course mastery* of older people 'through the greater occupational and financial opportunities' provided by education after high school (p. 173). Other authors indicated that although *mastery* is responsive to circumstances, it can also operate as a capacity (Skaff et al., 1996): it might buffer the impact of decrease in physical health on older people's well-being (Jonker, Comijs, Knipscheer, & Deeg, 2009), and it could buffer against the anxiety related to disability problems (Krokavcova et al., 2008). Furthermore, it was frequently reported that higher *mastery* levels are positively associated to physical and mental health outcomes, for example to lower risks of decline in functional ability (Kempen, Ranchor, Van Sonderen, Van Jaarsveld, & Sanderman, 2006), or to less depression (Krokavcova et al., 2008). Other researchers explained that a given level of *control* could be retained despite health decline; mainly through processes of selection, optimisation, and compensation (Baltes & Baltes, 1990) or through accommodative coping (Brandtstädter & Rothermund, 1994).

In relation to control in the health care setting specifically, authors often discussed the role of the doctor–patient relationship, by describing phenomena such as *shared decision-making* (Brody, 1980; Frosch & Kaplan, 1999), and *patient-centred approaches* in the medical practice (Mead & Bower, 2000; Rohrer, Wilshusen, Adamson, & Merry, 2008). Brody (1980) argued that whenever people are ill, less self-reliant, and need to depend on the doctor's decisions, this may undermine their sense of control and self-esteem, as well as their sense of dignity, which shows the importance of patient involvement in the care process. Indeed, some level of involvement was found to be important to many patients, based on data resulting from patient interviews or questionnaires (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Frosch & Kaplan, 1999). At the same time, however, there appears to be much variance between and within (older) patients concerning their wish to participate in medical decision-making: not all patients are equally willing to do so (Bastiaens et al., 2007; Brody, 1980; Frosch & Kaplan, 1999; Roberts, 1999). Generally, it was seen that if patients were more involved in their own care, they showed better health behaviours (Hochhalter, Song, Rush, Sklar, & Stevens, 2010) and improvement in control of chronic

diseases (Rohrer et al., 2008). In the literature these behaviours are often referred to as *self-management* (Lorig & Holman, 2003). Furthermore, examples of what patients could do to empower themselves in the health care domain were: 'participating in support groups, reading consciousness-raising books about health, and searching the internet for medical information' (Roberts, 1999; p. 86), although these reflected the writer's perspective and did not directly derive from patient perceptions.

So far, only few studies investigated the meaning or definition of control in health care from the perspective of the older adults themselves. Most of the studies that did, focused on isolated types of care such as: older people's views on *patient involvement* or *participation*, either in primary care (Bastiaens et al., 2007), in care during hospitalisation (Ekdahl, Andersson, & Friedrichsen, 2010), or when being assessed for receiving public home help (Janlöv, Hallberg, & Petersson, 2006). Among the factors that contributed to *involvement* or *participation*, according to older adults, were doctor–patient interaction, including communication/information (Bastiaens et al., 2007; Ekdahl et al., 2010); the caregiver's attitude towards the client (Janlöv et al., 2006) or willingness towards patient involvement (Bastiaens et al., 2007); personal characteristics of patients, such as physical or cognitive abilities; or contextual factors such as the availability and accessibility of the health professional, available time, and help of a third person (Bastiaens et al., 2007). Another study (Hibbard, Stockard, Mahoney, & Tusler, 2004) explored what care consumers needed in order to become effective and informed managers of their health and care. Based on opinions from professionals and chronically ill patients, required abilities appeared to be self-management of health conditions, collaboration with caregivers, maintaining functioning, and knowing how to access appropriate care. The focus of their study was on chronically ill patients from varying age categories, rather than on older adults in particular.

Research goal

The literature identified above either embodied ideas about control that are introduced by professionals or policy makers rather than by older patients in specific, or otherwise covered separate elements within health care. For this reason we conducted an additional study, wherein we aim to understand the concept of perceived control both a.) from the perspective of the target group, and b.) in health care in general, integrating various forms of care, and covering interactions with health care professionals as well as situations in the home setting. Adopting a holistic approach will ultimately do better justice to the complexity of elements that contribute interdependently to perceived control in the health care process of frail older adults. We undertook a qualitative study addressing the following research question: *what is perceived control in health care from the viewpoint of frail older adults?*

Methods

A qualitative interview study was conducted from March 2011 to November 2011, following a constructive Grounded Theory approach (Charmaz, 2006), encompassing: a.) *in-depth*

interviews with 20 older adults; and b.) *focus group discussions* with 12 older adults (in three separate groups).

Participants and sampling

Respondents for the in-depth interviews were selected from the Longitudinal Aging Study Amsterdam (LASA), an on-going cohort study that started in 1992 with 3-year follow-up cycles, aimed at investigating determinants, trajectories and consequences of ageing (Huisman et al., 2011). We drew a subsample from the total LASA cohort, according to three eligibility criteria: 1.) aged 65 or over; 2.) frail, i.e. scoring beneath predetermined cut-off scores, on at least two out of six functional domains (see Table 1, footnote^b) (Huisman et al., 2011); and 3.) having (had) experiences with professional and/

Table 1
Socio-demographic and frailty characteristics.

	Respondents – interviews (LASA) N = 20	Respondents – focus groups (Doetinchem, Amstelveen) N = 12
<i>Gender</i>		
M	8	5
F	12	7
<i>Age (range)</i>	65–96	66–87
65–74	3	8
75–84	3	3
85 +	14	1
<i>Marital status</i>		
Widowed	13	4
Unmarried	5	0
Married	1	8
Divorced	1	0
<i>Children</i>		
Yes	15	11
No	5	1
<i>Housing situation</i>		
(Semi) independent	17	12
Residential care home	3	0
<i>Education^a</i>		
High	10	6
Low	10	6
<i>Frailty^b</i>		(n = 10) ^c
BMI < 23	6	4
MMSE < 24	7	not measured
Vision	6	3
Hearing	10	3
Grip strength lowest quintile	10	6
Physic. activity lowest quintile	11	6

^a *Education*: the threshold for high education level was secondary general education or higher (for LASA and Amstelveen); intermediate vocational education or higher (for Doetinchem).

^b *Frailty*: BMI was calculated from height and weight measurements; Cognitive functioning was measured using the *Mini-Mental State Examination* (MMSE; range 0–30); poor *Vision* and *Hearing* were ascertained by asking respondents if they could recognize someone's face at a distance of four metres, and whether they could follow a conversation in a group of four people; *Grip strength* was measured in kilogrammes with hand-held calibrated dynamometers by summing the maximum values of the left and right hands; *Physical activity* was assessed by asking respondents how often and for how long they had walked, cycled, performed household activities and played sports during the two past weeks, after which the total time spent on physical activity per day was calculated by multiplying the frequency by the duration of each activity and dividing by 14 days.

^c (n = 10): Frailty was not objectively assessed in the Amstelveen respondents.

or informal care no longer than three years ago. To foster variety in our final in-depth interview sample ($N = 20$), we applied *maximum variation sampling* (Onwuegbuzie & Leech, 2007) and intentionally sought respondents from both genders, varying age categories and education levels (see Table 1, footnote^a). All data relevant for inclusion were obtained from the most recent regular LASA assessment which took place in 2008/09.

For the focus group discussions, we recruited ten older adults who were respondents in the Doetinchem Cohort Study (Verschuren, Blokstra, Picavet, & Smit, 2008), and two older adults were selected through a social care service for older people ('Vita Welzijn & Advies' which provides psychosocial advice and support), located in Amstelveen. Except for the MMSE data, the same information was available for the Doetinchem respondents as for the LASA respondents; therefore we could maintain our original criteria for these participants as well. Frailty data of the Amstelveen respondents were not available, but we informed the organisation's contact persons about our frailty criteria, who selected respondents accordingly.

Data collection and analysis

Data collection consisted of three interview rounds. Throughout the first round, we conducted 15 in-depth interviews for which the interview guide included global and open questions only, without covering any preconceived topics; the concept of perceived control was meant to be built only upon reported experiences from the target group. The in-depth interviews resembled everyday conversations in which respondents were stimulated to talk about (I) *their specific health and functioning problems*, (II) *their personal experiences with health care*, and based on this (III) *the degree to which they felt to be in control of the health care domain and how this was manifested in their experiences*, as well as (IV) *the factors they believed to influence control*. For all interview sessions, the *types of health care givers* that we focused on were 1.) General Practitioners (GPs), 2.) medical specialists, 3.) public home care professionals, 4.) non-medical professionals (e.g. physiotherapists, nurses, dentists), and 5.) informal caregivers (such as family members, friends or neighbours). We did not define any restrictions for the exact *types of care or help* given. The interviewer's role was to listen, probe, and elaborate on the specific actions, thoughts and feelings concerning essential topics that were brought up by the respondent, a technique called *intensive interviewing* (Charmaz, 2006). Throughout this round we analysed the interview data by means of *open coding* (Charmaz, 2006). While gradually moving forward to *focused coding* (Charmaz, 2006), and by using a *constant comparison method* (Glaser & Strauss, 1967) and writing memos, conceptual categories and theoretical notions emerged.

Subsequently, in the second round, two focus group discussions were organised with four and six participants respectively, from the Doetinchem cohort. Apart from open-ended questions about the meaning of perceived control and the factors influencing it, we presented anonymous cases and a series of statements related to perceived control. These were developed with material from the earlier in-depth interviews and were used to stimulate the discussion among the participants, as well as to validate the conceptual categories

that we identified during the first round. To analyse the data from the group sessions we applied focused coding, and meanwhile advanced to a more sophisticated level of coding wherein relationships between categories are sought in order to integrate all focused codes and consequently theorise the data (*theoretical coding*) (Charmaz, 2006). Based on this advanced level of coding and on the memos (i.e. the ideas about conceptualisation noted down throughout the coding process), an extensive memo report was written, to explain the relationships and to create an analytic story with coherence. Hence our conceptual model could be further developed.

Hereafter, we conducted a final set of interviews: five in-depth interviews with LASA respondents and one group session with the two participants who were selected with help of the social care service 'Vita Welzijn & Advies'. We planned this third round to further explore some of the conceptual categories in a sample of older adults with poorer physical functioning and more chronic diseases to arrive at even more solid insights concerning these particular categories; this technique (*theoretical sampling*) can be used whenever categories need further elaboration or refinement, and is done by sampling a particular group of respondents that can provide the relevant material for these categories (Charmaz, 2006).

When data saturation was reached we finalised our conceptual model, incorporating subcategories, broader categories, and overarching themes that can be regarded as the elements that constitute the perception of control in health care.

The individual interviews were carried out by either the first or third author, whereas both these authors were present in each focus group session. All interview sessions lasted for about one hour to two and a half hours. The in-depth interviews were held in the respondents' homes, while the focus group discussions took place in a room of the local Public Health Service in Doetinchem (a service directed at the enhancement of the local public health), or in a room of the social care service 'Vita Welzijn & Advies' in Amstelveen. Upon permission of the respondents, the interviews were audio-taped and transcribed verbatim. The coding of the interview data was performed with help of the software ATLAS.ti 5.2.

Validity and reliability

The *validity* of this qualitative study was supported by *methodological triangulation*, i.e. a combination of focus groups and individual based interviews was used. Focus group discussions enabled us to exchange experiences and further elaborate on the various themes that had emerged. Moreover, the validity was fostered by a series of *member checks*: a random subsample of respondents (5 out of 32) provided input after having read their personal interview transcript and analysis document; another subsample (6 out of 12 focus group respondents) gave feedback on a summary of our conceptual model. The interviewees involved agreed with the contents, and only some introduced small nuances.

Reliability was warranted as the first series of interview transcripts ($n = 5$) were independently coded by two researchers (the first and third author), to develop a consensus-reached coding style. A random subsample of all

other coded transcripts, produced hereafter, was double-checked by one of the co-authors (M.H., G.W., D.D.).

Results

Subjects

We interviewed thirty-two older adults, either individually or in a focus group. The respondents varied in age, gender, education level, and were spread over four culturally diverse (urban as well as rural) areas in the Netherlands. Socio-demographic and frailty details are presented in Table 1. The majority of our respondents lived independently and was widowed. All of our respondents had experiences with professional care (currently or in the previous three years); often this concerned more than one type of care, but in most cases the combination was not perceived as complex by the interviewee. In the case of home care, we met respondents with professional care, and some who received informal care, such as assistance in household from a person in one's social network. A majority mentioned to have regular or at least occasional help from significant others, with respect to their functioning or arranging and using professional care. Only five reported to receive substantial informal help on a frequent basis.

Perceived control: a conceptual model

Initially, the term *control* evoked a variety of associations among our respondents, such as 'being in charge', 'organising care', 'estimating whether you can do it on your own...or whether to seek help', 'being critical on what is advised', 'discussing with the professional and bring one's views into alignment'. These associations seemed to refer to a form of actively exerting control over their care by themselves in the sense of organising the various aspects and participating in health care-related decisions. A few respondents attempted to define the concept (1, 2).

1. 'Well, it's the feeling that I'm the one who chooses whether to go to a doctor. ... and also that I can anticipate where I'm heading [regarding the health situation]. ... and to take responsibility for your own decisions, because it's possible that I don't ask for help whereas others think that I should.'

[(f, 65 years)]

2. '... just thinking in a practical way about what I need. Something needs to be done, and I must try to do it [given a deteriorating health situation]. ... At a certain moment, you make a sort of plan, and I should follow up on it.'

[(f, 85 years)]

However, not just the respondents' own efforts seemed to influence their perception of control. Perceived control appeared to reflect the feeling or belief of older adults that their health care was brought *under control*, with or without help from sources other than themselves. We identified a set of diverse constituting factors in relation to older adults' perceived control, which are presented in a conceptual model (Fig. 1). We classified these as either internal factors, i.e. those as perceived to be under influence of older adults themselves,

or external factors, i.e. older people's perceptions of the outside world – others and systems – in the light of their health care. The factors and their specifications will be described in the following paragraphs.

Self-confidence in organising professional and/or informal care

When elaborating on their experiences, the respondents referred to various activities related to organising care and participating in care decisions. For example, they reported that they: decided whether, when and how to initiate health care and what type of care; expressed wishes and were involved in intervention or treatment decisions; asked questions or collected information; could understand the information given; oversaw and/or arranged their health care appointments and health care-related administration; stood up for themselves in discrepant health care situations; thought about – and documented – wishes for future health care or end-of-life issues; and thought about – and planned on – how to act in health emergency situations.

Although many respondents reported to handle most of these activities quite successfully, a recurrent concern was determining the right time to initiate a more intensive form of care (e.g. homecare or admission to a residential home). Some people felt that the need for help would rise in the near future, but dreaded the consequence of restricted privacy or freedom, and therefore experienced uncertainty (3). It was also believed that postponing professional care, because people wanted to hold on to their independence for too long, would compromise one's health. In this light a 65 year old woman mentioned that control 'is also about being able to hand it [the care for one's health] over to a professional if you cannot do it yourself any longer'.

3. 'Because you don't want to have all these people [homecare personnel] in your house, right? You lose your freedom, your own space. So it's difficult to judge: when will I actually do it [organise homecare]?'
[(f, 81 years)]

A few respondents explicitly stated that, overall, they were no longer in control of their health care. Characteristics of these respondents were an older age (above 86 years), substantial limitations in physical functioning, cognitive frailty (MMSE < 24), and living with home adaptations or in a residential home. They all expressed a similar view on control: it is normal, acceptable, and even pleasant and 'good for your own health' (m, 91 years) to leave it in the hands of other people whenever you are no longer capable of exerting control yourself. However, while certain tasks were taken over by others, this group of respondents seemed to experience some level of control in another way; they mentioned that they were still able 'to discuss' or 'think along' (m, 96 years); or to express their needs and wishes to the caregivers (m, 87 years).

Additionally, we found that not all of the respondents with cognitive problems felt that control was in the hands of someone else. A few of them explicitly emphasised their ability to 'think', or were inclined to act as if they were fully capable of keeping control and being independent – even if this did not seem in accordance with the actual situation. It appeared that these persons had higher SES levels, had higher previous

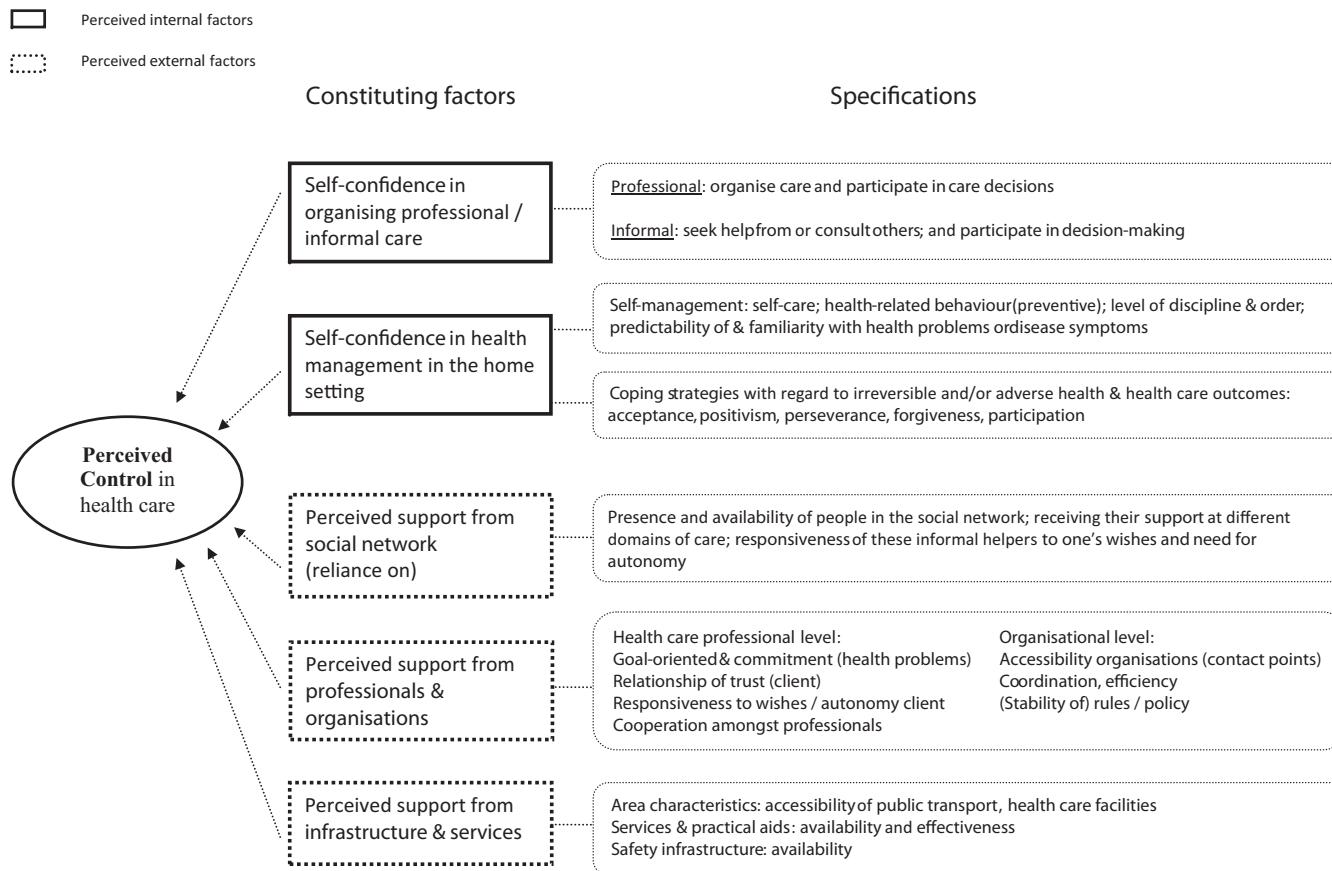


Fig. 1. Conceptual model for the perceived control in health care among frail older adults.

occupational levels, and had a more ambitious attitude, than the remaining ones with cognitive frailty and who did not perceive to be in control themselves.

Within the scope of the *informal* health care experience, daring to *ask for help* or *consult others* (e.g. family, friends or neighbours) was regarded by many respondents as beneficial for the health situation, and therefore seen as a form of control. Paradoxically, asking for help also triggered feelings of ambivalence among most of our interviewees. In this light we observed a tension between the wish to hold on to personal control for as long as possible and anticipating the need for more support. Furthermore – whenever informal care was received – being able to discuss one's wishes (*participate in decision-making*) with the informal caregivers was believed to enhance perceived control.

Self-confidence in health management in the home setting

Taking care of one's own health in the home situation was a theme that came up often during interviews. Some respondents described how they managed their disease symptoms (*self-care*) by engaging in prescribed physical exercises, carefully handling their medication, or being inventive in overcoming their disabilities. Also, *engaging in health-related behaviours* to take care of their own health for preventive reasons, e.g. maintaining a healthy diet, exercising, being aware of unhealthy habits such as smoking, and even tidying up their house, was mentioned by many. Respondents who spoke of successfully engaging in these behaviours seemed to feel that they were responsible and in control. Some, however, explained that they had gone too far in trying to remain independent and taking care of themselves, putting too high a burden on themselves; they believed that this excessive form of control might undermine rather than benefit their health.

Some respondents mentioned an underlying attitude, striving for *discipline and order*, which stimulated them to act responsibly and helped them to hold on to health-related and self-care behaviours, giving them a sense of structure, for example by keeping regularity in their activities (4).

4. 'People should pay attention! I'm very... How should I put it? Strict in this. Yes, you should do a lot of things yourself. ... No, it's just a matter of living a sober life. Time matters; do everything on time. And, well, live according to a certain rhythm. And then... I believe that, in due time, it will become automatic. ... Be consistent. It's all about being consistent.'

[(f, 85 years)]

Whether or not self-care behaviours are easy to adhere to, seemed to be related to the perceived *predictability of and familiarity with health problems or disease symptoms*. When causal and eliciting factors of these were known and thus the course of the health problem or symptom was somewhat predictable, people learned how to cope, which facilitated self-care (5).

5. 'Well, I know that if I'm stressed, I can get pains in my chest, so I make sure I carry this thing [inhaler] with me, try not to panic. ... I think I can do it [manage the symptoms properly] mainly because I know all about it. I know what can happen, or what is happening at that moment, so I also know that I really shouldn't panic. Oh, and because I've been

through it before, I know that the medications will work, if I need them.'

[(f, 65 years)]

Perceived control in the home situation also depends on applying adequate coping strategies. If a health situation appeared irreversible or in case of adverse treatment outcomes, respondents remarked that it was important for them to handle this in a constructive way, by *acceptance*; retaining an *optimistic* – or down-to-earth – *attitude*; or *perseverance*; or by *forgiving* caregivers whenever minor mistakes had been made, which allowed them to remain psychologically calm or stay active in their lives rather than to fall into helplessness. *Taking part in activities of daily life*, e.g. trying to stay active or at least up to date of societal developments (6), was also considered as a way of coping with decreasing health and would stimulate perceived control.

6. 'It's a matter of luck that I can still do so much, that my mind is still clear, that I can say something, that I can talk to them [caregivers]. ... I can chat with my children about the weather, about what's going on in the world ... that's what I also talk about..... I can take part in things, to a certain extent.'

[(m, 96 years)]

Perceived support from the social network

In most interviews, respondents reported to have received support in the health (care) domain from significant others to a greater or lesser degree. *Support* included a wide range of activities, i.e. instrumental tasks, support in contacts with professional health care, and the provision of information (advice) and emotional support.

Despite the decline of some of our respondents' abilities, their perceived control in health (care) was often found to be retained due to this very experience of being looked after. Receiving support helped to strengthen the perception that health (care) is under control (7). Even the expectation alone that others would come to the rescue when needed, contributed to perceived control, because it enhanced a sense of safety.

7. 'If you can no longer do it yourself, then it's important that you have someone, someone you know well, who's capable and who can arrange things for you. That's very important.'

[(m, 96 years)]

The majority of respondents with children explained that they could rely on their children (-in-law). Other potential caregivers or helpers mentioned were spouses, friends, neighbours or remaining family members. Several respondents feared bothering their relatives, friends or neighbours in their 'busy lives' and some claimed that their children needed their own freedom (8).

8. 'Well, some mothers – or parents – they chat for hours with their children. But you shouldn't do that. You shouldn't keep them from their work or their own affairs. And you shouldn't be a burden to them; you should take care of yourself.'

[(f, 80 years)]

Nonetheless, many respondents experienced that help was often automatically and promptly initiated by members of their social network. Support from children was found to be more self-evident than help from neighbours and friends which could engender stronger feelings of inconvenience or fear of burdening them. This was reinforced by the fact that some of these were from the same age category and might face limitations in functioning themselves.

Interviewees who were single and had no children (or children living far away) more often needed to draw upon other resources. This may decrease perceived control, as in some cases efforts were required to make a situation manageable, e.g. needing to make drastic decisions such as organising professional help, and anticipate this in an early enough stage.

In addition to the actual *presence* of a social network, which in itself increased perceived control, the degree to which these significant others were *available* in terms of geographic distance, willingness and capability proved important, as did their *responsiveness to one's wishes and need for autonomy*.

Perceived support from health care professionals and organisations

On the health care professional level, respondents spoke of experiences that seemed to influence their perceived control. First, we found that it was important for respondents that health care professionals showed *goal-oriented behaviour* and *commitment* when handling health problems. One obvious example came from a respondent (m, 74 years) who experienced great discontent due to the perception of an unstructured approach by several professionals. He advocated that health problems should be tackled purposefully and professionals should provide some perspective to their patients (9).

9. 'It's a chain of events. You go from one physiotherapist to the other, but no-one takes you by the hand and brings some structure to your care. And who says: 'We're here now, we should be able to manage.' ... You're being treated and after a while they let you go ... until you have to come back again ... and then you get a number of treatments, a number of sessions. Then that stops, also because there's no money left. And so it goes on and on. We now have – for the first time – a GP who takes the initiative, who doesn't leave you dangling so much.'

[(m, 74 years)]

Related to this topic was the wish that health care professionals should initiate adequate care, or arrange for additional professionals to be involved during the care trajectory. Also, some respondents reported feeling left alone; not being monitored throughout or at the end of a care trajectory, and feeling that professionals did no more than they were strictly supposed to do (10). These experiences compromised their sense of security and safety, and thereby threatened perceived control.

10. 'Look, if they [homecare personnel] come, there's a lady who brings a book with her and writes things down in it also those girls, if there's something special. Then they write down a word or two. But nobody thinks of calling me up after a while, to ask how I'm doing.'

[(f, 86 years)]

Furthermore, perceived control was found to be positively influenced by a *relationship of trust* with the health care professional: one that is established when a professional met characteristics such as maintaining a personal and open approach (listens to and understands the patient's perspective), taking his/her patient seriously, having enough time, using humour, and being empathic.

It also appeared that the *responsiveness* of a professional to a *client's wishes or to the need for autonomy* could influence perceived control. Some respondents reported to highly appreciate being informed adequately on matters concerning their health problems or treatment (11), because this prevented them from feeling insecure.

11. 'I get along extremely well with my lung specialist. ... He tells me everything in detail. He's the first person to tell me what exactly is going on with it [my disease]. ... If she [the cardiologist] had just said 'Your heart's fine, you're probably just having spasms', I would have been satisfied. But now she keeps on saying 'No ma'am, I can do nothing for you. You, er, you... I can't find anything'. I find that unsatisfactory, because what she's doing in fact is abandoning you to your fate.'

[(f, 65 years)]

Our respondents differed in the extent to which they wanted to participate in the treatment decision-making process. While some felt comfortable trusting the caregiver's treatment advice or diagnosis, others were in favour of a 'middle way', and some even preferred an interaction that resembled the 'informative model', where the doctor informs and the patient decides. This variety was seen in the interaction with physicians, but also in relation to home help personnel. We found that perceived control was enhanced whenever care professionals were sensitive and considerate towards their clients' participation wishes.

Cooperation among health care professionals arose as an important topic that is related to a sense of control. Perceiving adequate communication between care professionals made respondents feel safe and in good hands. The opposite was experienced by one of the respondents (f, 87 years), since her medical specialists did not align their views on the medication prescription. This led to a slight feeling of disturbance as she felt the urge to intervene in order to prevent that damage was brought to her health.

On the organisational level, topics that emerged included, first, *accessibility of health care organisations* (e.g. knowing what departments to contact and how to get in touch with these). In this respect some respondents noted that the information they needed to call in health services was easy to trace, for example through community leaflets, or experienced that specialised nurses in the hospital could provide them with the information they needed. A second topic was the *coordination and efficiency* of an organisation when care is being arranged (other types of care prompted). Some respondents positively evaluated their experience that care or practical aids were automatically initiated by an organisation or by the hospital when needed. As a consequence, these respondents experienced their needs for care as being met quickly and easily, which helped them perceive that their health care was brought under control. The

last topic that we identified on the organisational level was feeling restricted by (change of) *rules or policy* of the health care system (12), including the bureaucracy and possible complications in everyday practice of care that may follow from this, and which was found to threaten perceived control.

12. 'Control is taken away from you by rules. ... I can be in control, but there are so many things that you can't influence, they just happen. ... There are rules everywhere. You get a new government, and so you get new rules and regulations. And it just happens, whether or not you agree with it.'

[(m, 80 years)]

Perceived support from (health care) infrastructure and services

Many of the interviewees talked about being supported by either the *accessibility of public transport or health care facilities*, or the *availability of services or practical aids* that they would use to compensate for their loss of functioning, such as delivery and transport services or mobility and vision aids (13). These could help the respondents to experience control over their health and living situation in general. In addition to the availability we found that the *effectiveness* of these services or aids were important, because some of the respondents noted that certain aids did not meet their needs at all, whereas others felt tremendously supported because of the adequate functioning of the aids or services received.

13. '... An occupational therapist was sent to me, and he gave me all sorts of aids: a pen I can hold more easily, a special pair of scissors, furniture raisers – because I now can't get out of bed that easily – a kitchen stool ... and this all gives me so much pleasure. It's really wonderful; these people are so resourceful.'

[(f, 74 years)]

One topic brought up by several respondents was the *availability of a safety infrastructure*. Some of them explicitly noted to worry about emergency situations, such as suddenly becoming unwell or a fall accident while being alone. Some of the respondents reported to be prepared as well as possible, e.g. to have arranged a 'signals' system with their neighbours; or in some cases people felt safe as they carried around an alarm button. The perceived lack of an adequate solution for future emergency cases elicited fear, and had a major negative impact upon perceived control.

Discussion

This qualitative study sought to investigate the concept of perceived control in health care from the viewpoint of frail older adults, aged 65 or over.

The term 'control' was initially associated by our respondents with *personal control*, i.e. the degree to which they were the active agent in their own care process. They described this as being engaged in activities that pertain to organising care and participating in decisions. However, a further reflection on care experiences led to a more detailed concept that also incorporated external influences. In sum, *perceived control* reflects the feeling or the belief that health care is *under control*,

arising from multiple constituting factors: i.e. *self-confidence in organising professional and/or informal care*, *self-confidence in health management in the home setting*, *perceived support from people in the social network*, *perceived support from health care professionals and organisations*, and the *perceived support from (health care) infrastructure and services*.

Our findings indicated that the level of perceived control was dependent on the factors that constitute it: when all factors were favourable (sufficient support possibilities as well as confidence in own abilities), perceived control was high. Whenever some factors were less favourable, respondents appealed to their strengths or beneficial circumstances, i.e. to those factors that were developed more strongly, in order to compensate for the weaker ones.

In particular, some benefitted from an adequate supporting social network, sharing tasks with significant others, or handing over actual control to compensate for loss of (confidence in) their own functioning. This principle of control by a proxy was described earlier as yet another form of control; for instance Walker (2001) stresses the importance of social support whenever an individual's health condition is compromised. Following Walker, we argue that social support might complement or replace personal control, and can be perceived as beneficial or even required, for example whenever physical or mental fitness substantially decreases. Indeed, the respondents in our study who lived in a residential home or in their own home with extensive home help, mainly experienced that control *needed* to be maintained in a team. We argue that, under these circumstances, full personal control could actually yield feelings of stress or heavy demands, as is described in Averill (1973) and Rodin (1986). In contrast, some other respondents clearly had a strong confidence in being able to handle their own health care situation. Especially those who lived alone without a supporting network and who were used to fall back on their own skills throughout their lives, strongly emphasised their abilities. Our interview data imply that as people get older and face an increase in illness and/or disability, the external aspects of control – especially support from the social network – become more important, whereas the internal or 'personal control' aspects become less so. This is in accordance with the finding of Schieman and Turner (1998), who report that age-related health problems generally cause a decrease in the overall sense of mastery in life. In addition, we saw how experiences with professional health care could further add to or impede older people's sense of control.

The key notion that *perceived control* is based on the combination of perceived internal and perceived external influences is supported by other studies that equally described personal and environmental aspects of comparable concepts such as involvement (Bastiaens et al., 2007), empowerment (Roberts, 1999), or resilience (Wiles, Wild, Kerse, & Allen, 2012). Indeed, many of the aspects mentioned in earlier studies were incorporated in our conceptual model, e.g. self-management of symptoms (Hibbard et al., 2004), the attitudes of and relationship with health care professionals (Bastiaens et al., 2007; Clark, 1987; Ekdahl et al., 2010; Janlöv et al., 2006), education (by the professional) and information seeking by the client him/herself (Hitlin & Long, 2009; Roberts, 1999) but only if wished, accessibility of care (Bastiaens et al., 2007; Hibbard et al., 2004), and the role of social support in

perceived control (Clark, 1987; Sinha, Nayyar, & Sinha, 2002; Walker, 2001).

In contrast to earlier research, the focus of our study was on overall health care received by frail older adults, including various types of care and a wide range of related aspects. We found that people claimed that they themselves or (together with) significant others played a key role in organising care, and not the care professional. This is in line with the conclusion from Lyons and Zarit (1999), who state that regardless of the degree of the availability and eligibility of formal services, the informal caregiver – if present – stays generally responsible for seeking out such services, not the professional. When reflecting on perceived control in relation to the *informal care*, our study shows that providing (instrumental, emotional) support or care is a pathway through which these informal helpers can positively contribute to an overall sense of control. Moreover, informal helpers can function as the '(co-)organisers' of professional care, for example by assisting in making appointments and communicating with care professionals or organisations, helping decide on care or treatment options, or by assisting in more practical aspects such as filling out paperwork and providing transportation. In both situations, experienced responsiveness from these helpers to the older adult's wishes and sense of autonomy is crucial for perceiving control.

Respondents regarded their experiences with *professional care* provided by GPs, specialists, and home help mostly as equivalent but separate events: the kinds of issues raised by the respondents appeared to be quite similar across the various types of care professionals; at the same time, however, the experiences with different types of professionals were hardly related with one another by the respondents and seemed to be considered as independent cases. In light of perceived control, these various care events had in common that our respondents felt that they needed to rely on their professionals' expertise, and that there was a certain amount of variety to which the respondents participated in decisions. We noticed that especially the remarkable situations, when receiving professional care, would make people feel aware of (a lack of) control. With these remarkable situations we refer to extremely positive (control enhancing) or, instead, negative (control disrupting) experiences regarding the topics that we identified both on the caregiver level (i.e. goal-oriented behaviour and commitment, trust, responsiveness to the client's wishes, cooperation), and on the organisational level (i.e. the well-structuredness of the system, efficiency of communication, and clarity of rules) as was explained and illustrated in the results.

Since control over health care is also in the public debate associated with an active attitude from clients themselves, we wish to further reflect on this view.

First, the meaning of control to our respondents appeared to be relative to their functional abilities; even the respondents with poor functional abilities stated that they had some degree of personal control (e.g. to 'think along'). Therefore we believe that perceived control can refer to full control in both thinking and acting, but also to less active forms of control, where only cognitive processes play a role.

Second, although in general our respondents highly valued their independence, the *motivation* to decide on actual health care options differed among our respondents and

appeared to be dependent of how they felt both physically and mentally. This is in line with the conclusions from other researchers (Bastiaens et al., 2007; Roberts, 1999; Lachman, as cited in Rodin, 1986; Rodin, 1986) that older people form a heterogeneous group when it comes to preferences on participation in decision-making. Not only differences in culture (Blackhall, Murphy, Frank, Michel, & Azen, 1995; Roberts, 1999) or personal differences may underlie this observation, but we also believe that participation wishes may decline over time as people feel that physical or mental fitness is decreasing, which is supported by earlier work (Bastiaens et al., 2007; Say, Murtagh, & Thomson, 2006). Therefore, sharing or handing over control might in some situations benefit older people's sense of safety and should not by definition be regarded as negative.

Third, we found that perceiving a certain level of control in health care was often a matter of adapting mentally, a mechanism that is referred to in the literature as secondary control (Heckhausen, 1997; Rothbaum, Weisz, & Snyder, 1982), because many of our interviewees dealt with irreversible setbacks in their health status or care outcomes that were hardly under their own influence. This coping phenomenon can also be interpreted in terms of *accommodative coping* (Brandtstädter & Rothermund, 1994), which means that people tend to downgrade the importance of their goals in life, whenever their abilities to achieve these ceased to exist. Resembling mechanisms that we saw whenever our respondents faced disappointments in their experiences with receiving care, were adjusting expectations or simply forgiving their professional caregivers for minor mistakes.

These reflections support our idea that perceived control in health care cannot by definition be realised by full actual personal control.

Strengths and limitations

In our study we addressed the perspective of frail older adults with regard to control in the health care domain. This may provide a significant contribution to the on-going political debate that emphasises older people's self-reliance, and can therefore be counted as a strength of this study. Moreover, our study is among the first to integrate the combination of different types of care and aspects when studying perceived control from the viewpoint of older people.

A limitation of this study concerns a possible selection bias. We interviewed those who were capable of enduring an intensive interview session; therefore we may have spoken with people who are in relative good health, even though we selected older adults who were already frail. This prevented us from sufficiently exploring perceived control among those people for whom control may be really an issue, i.e. older people who use more intensive or more complex combinations of care, or for those with severe cognitive limitations.

Conclusions and implications

Perceived control in health care among frail older people is a subtle and complex concept. It is constituted by the experience that health care is *under control* and not only based on people's perceptions of their personal control, i.e. their self-confidence on the domains of organising care and managing their health in their home situation. Specifically, older adults' perceptions of

control also appear to be connected to feeling secure, which comes from both professional and informal external support and the way in which these are provided. This seems to be at odds with policies that aim at promoting self-reliance and independence as much as possible. In this context, we argue that the need for support from one's social network is inherent to growing old and frail, as is the increasing need for a professional system that provides a basic degree of care as well as structure and clarity to older people regarding the care that is available to them. A combination of informal and professional support might prevent older people from deterioration of their independence and keep a certain level of perceived control, in case of diminishing health.

Our model may provide guidance within the setting of clinical practice or policy planning. We hypothesise that there might be specific subgroups of older adults who are at risk of perceiving a decrease in control and to whom special attention should be paid: those with few resources (minimal informal support, living alone, and limited or declining abilities) or a sudden setback in their health or the network situation. Also those who cope with substantial frailty, but who have difficulty accepting that their living situation became untenable, or – even worse – refuse help, might form a group that is at risk for accumulation of problems. Furthermore, we argue that encouraging people by default towards self-reliance might have an adverse effect on some people's perceived control as this could undermine their feeling of a stable and controlled health care situation. Therefore, we strongly recommend that caregivers and policy makers pay attention to older adults' individual differences, and take into account the external factors that can assist older adults in perceiving control in their health care.

In the short term, our conceptual model could serve as a basis for the development of a measurement instrument, for instance in the form of a self-reported questionnaire for (frail) older adults. We believe that when constructing such a measurement instrument, it is important to reflect our finding that perceived control in health care is clearly a multi-dimensional concept. The challenge will be to develop a questionnaire that has a broad scope, is sufficiently distinctive from existing instruments, and has adequate psychometric properties and internal consistency. Such an instrument would enable future quantitative research on the topic of health care-related perceived control of (frail) older adults.

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